

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

Children with severe disabilities have a definite impact on the lives of their family members. The majority of the adolescents with a sibling with a disability, together with their parents, have received limited professional support. The limited professional support received by them, manifests in the adolescents' superficial knowledge of the sibling's disability and its consequences. Their superficial knowledge of the disability and its consequences, affects their understanding of the disability and it increases their feelings of uncertainty regarding the sibling with a disability. Crnic et al. (1983), confirms the importance of professional support in the understanding of the disability.

Most of the adolescents are not freely expressing their feelings regarding the sibling with a disability and, combined with their superficial knowledge of the disability, it adds to their feelings of guilt. They feel guilty about their feelings towards the sibling with a disability, which leads the young adolescents to feel lonely and isolated (Cotterell, 1996; Abell & Gecas, 1997).

According to the perceptions of the young adolescents, members of their peer group support them better than their parents. It is normal for adolescents to rely on the support of peers, although they still have an emotional attachment to their families. The subjects of the study report limited family interaction, which links to their perceived limited parental support and their inability to freely express emotions. This inability to express their emotions, leads to the projection of negative feelings onto other issues and the avoidance of any negative emotions.

Adolescent siblings need adequate professional and parental support to cope with the stressor of having a sibling with a disability. They need to have the opportunity to voice their feelings regarding the issue. Powell & Gallagher (1992) state that support groups for siblings of children with disabilities might facilitate coping responses and help in the process of adjustment.

5.2 Critical evaluation of this study

- Little is known about the coping behaviour of the adolescent siblings of children with disabilities and the study focused exclusively on children in early adolescence (12-15 years).
- The open-ended, unstructured interview provided the subjects with the opportunity to voice their exact feelings regarding the stressor of having a disabled sibling, although it complicated the data analysis.
- Approximately 25% of the analysed data was counterchecked by an external rater, which improves the reliability of the data obtained. However, if there was a larger data set and if more than one method of measurement were used, these strategies could have added to the reliability of the results.
- If more than one interview could have been conducted with each of the subjects over a period of time, it would have enhanced the data, especially when considering the dynamic nature of stress and coping.
- Although adolescents are at a self-conscious age that might have influenced the reliability of the information obtained regarding their personal feelings, caution was taken to ensure that all participants felt at ease before the interviews were conducted. The interviews were conducted within an informal atmosphere at the homes of the subjects.

5.3 Recommendations

Recommendations regarding further research and clinical practice are outlined in the next section:

5.3.1 Implications for further research

- A study on the sibling relationships of young adolescents with normal siblings can be done in order to identify trends within sibling relationships of adolescents who don't experience the stressor of having a sibling with a disability. The results can be compared with the results of this study.
- Research on the nature of the interaction between the young adolescents and their siblings with disabilities can be done.
- Research to determine the knowledge and understanding of siblings and parents regarding the disability of the sibling and its consequences might provide valuable insight into the lives of families with a member with a disability.
- A study can be done to determine the needs of the families of children with severe disabilities, with regard to professional support services, e.g. counselling, family support groups, etc.
- Specific siblings of children with severe disabilities can be studied over a longer period of time, e.g. early childhood to adolescence and a comparison could be drawn between their coping responses during different developmental stages.
- A study can be done specifically about the social support the siblings with disabilities receive from their peers. Especially in the case of adolescents, it will provide valuable information regarding the exact influence peers have on them and how they mediate or impede the coping responses of the siblings.
- The adolescent siblings of children with disabilities experience feelings of guilt about their feelings regarding the sibling with a disability. A study that examines these feelings of guilt can be conducted.

5.3.2 Implications for clinical practice

- In general the parents of children with severe disabilities are responsible for informing the other siblings about the disability and its consequences. Parental attitudes towards the disability influences the siblings' perceptions and coping responses, which highlights the importance of the following:
 - the parents need to be provided with adequate and accurate information regarding the disability and its consequences, in order to provide the other siblings with information about issues concerning the child with a disability;
 - the parents need more professional support, especially regarding issues concerning the disability and its consequences, as well as the acceptance of the disability and coping with the stressor.
- The adolescent siblings of children with severe disabilities are not freely expressing their feelings, they have feelings of guilt about the sibling with a disability and they receive limited professional and parental support. These issues can be addressed as follows:
 - professionals need to focus on the needs of young adolescents with regard to their siblings' disabilities and its consequences;
 - siblings need guidance on active coping responses in coping with the stressor of having a sibling with a disability;
 - sibling support groups may provide siblings of children with disabilities with peer support, as well as models of coping with the situation.